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The impact of screening for intellectual disability in paediatric services: A modified Delphi approach

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Aim: To develop a consensus framework to evaluate the impact of screening for intellectual disability (ID), using the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) in paediatric neurodevelopment clinics.

Methods: A modified Delphi survey with four phases (literature review; initial development of framework [participants = 11 parents, 8 professionals]; qualitative interviews [participants = 4 parents, 15 professionals]; questionnaire development [participants = 31 parents, 14 professionals] was used to develop the consensus framework. The framework was used to evaluate the impact of screening on 6 paediatricians and 31 parents of children who had participated in a previous paediatric screening project.

Results: Twelve of the original 20 items were retained based on levels of endorsement of 60% or above. Direct benefits of using the CAIDS-Q were: indicating the child's level of functioning, increasing awareness of ID, helping to identify children with ID and identifying potentially vulnerable children. Benefits related to subsequent diagnostic assessment were: promoting greater understanding of the child, identification of support needs and receipt of support, particularly for the child at school.

Interpretation: The use of the CAIDS-Q had a number of direct and indirect benefits for children, families and services as reported by parents and paediatricians.

What this paper adds

- A framework was developed to evaluate the impact of screening for intellectual disability.
- Twelve items were retained based on endorsement levels of 60% or above.
- Using the CAIDS-Q had direct and indirect benefits for the child/others
- Direct benefits included increasing awareness and identification of intellectual disability

- Indirect benefits included increased identification of support needs and receipt of support

Short title: The impact of using the CAIDS-Q

Key words: screening; intellectual disability; paediatric services; Child and Adolescent Intellectual Disability Screening Questionnaire; impact

People with an intellectual disability face many challenges due to their significant difficulties with intellectual and adaptive functioning. They also experience health inequalities[1]; increased risk of behaviours that challenge[2] and difficulties with emotion recognition.[3] Families/carers may have to deal with a range of emotional, physical and financial consequences of caring for children with complex support needs.[4] Early diagnosis of intellectual disability has many benefits, including facilitating the timely assessment and understanding of the child's needs and the provision of support to address these.[5,6,7] There is growing evidence that comprehensive early intervention approaches can result in improvements in social, adaptive and cognitive functioning of the child and increased confidence and optimism in the parent (see Guralnick[8]). By contrast, diagnostic delays can be associated with poorer parental psychological wellbeing and reduced satisfaction with services.[9]

Despite the advantages of early identification of intellectual disability, diagnosis continues to be variable, with some children experiencing significant diagnostic delays.[10] Many young people may also have their intellectual disability unrecognised in situations where they are likely to be particularly vulnerable, such as within criminal justice services.[11] Screening questionnaires may be useful to facilitate the diagnosis of intellectual disability, for example, where limited resources make conducting full diagnostic assessment difficult; where an estimation of intellectual and adaptive functioning is sufficient, such as for research purposes; to help services with long waiting lists prioritise diagnostic assessment (see[12]) or where a large number of people may need to be screened to identify potential vulnerability.[11]

One available screening measure is the Child and Adolescent Intellectual Screening Questionnaire (CAIDS-Q[13,14]). This has been found to have good psychometric properties when used in a range of clinical and forensic settings,[11,14,15,16] including paediatric services,[17] but little is known about the impact of using screening questionnaires for intellectual

disability and how best to measure it, given the range of purposes that screening questionnaires might be used for. The present study, therefore had the following aims:

- To develop a consensus-based framework for identifying the impact of using screening questionnaires for intellectual disability on individuals, their families/carers and services
- To use the agreed framework in order to meaningfully assess the impact of screening on those who participated in the paediatric screening project[17]

Method

Ethics

Ethics approval for the study was obtained from the first author's university and from the NHS Research and Audit Department in the area the paediatric screening project took place. Informed consent was obtained from all participants for all stages of the study.

The paediatric screening project

The 'paediatric screening project' was conducted in paediatric services in Scotland,[17] with the aim of validating the CAIDS-Q in paediatric settings. A total of 181 children were screened using the CAIDS-Q and subsequently underwent assessment of their intellectual and adaptive functioning to determine if they met the criteria for intellectual disability. Feedback was then provided to the parents and paediatricians. Fifty-four of the participating children met the diagnostic criteria for intellectual disability and for some their diagnosis was a result of taking part in the screening project.

Design

The study, conducted in 2018, used a modified Delphi technique. Traditionally, this entails creating expert consensus about an issue by asking relevant stakeholders to respond to a

series of survey questions using an iterative approach in which responses are anonymous. The process involves a number of waves or phases to which participants contribute.[18] The Delphi approach is increasingly used in health care settings and is a particularly useful approach where there is limited existing research or consensus, the topic being addressed involves subjective opinions or values, and where a large range of stakeholders who differ in their experiences and perspectives and are geographically dispersed all have legitimate viewpoints. The Delphi approach views diverse opinions as equally valid, thereby avoiding power differences between participant groups.[18,19]

This approach has been adapted in a number of ways by researchers, including using responses to open-ended questions[18] and literature searches[19,20] to inform the topic in question. A purposive sampling approach was used throughout in order to include individuals with the knowledge and experience to meaningfully contribute to the research[21] i.e., to identify potential and actual areas of impact of screening for intellectual disability. There is no recommended sample size for Delphi approaches, with suggested numbers ranging between 10 and 50.[22] In the present study, there was a minimum of 19 participants in each phase.

Response rates varied from 100% of those invited to participate (for teachers in phase three), to 72% (31/43 contacted for whom contact details were still valid) for parents in phases four and five. It was not possible to calculate an exact response rate for all participants in all phases, as it became apparent that some potential participants circulated the invitation email to other colleagues. In other cases, the target individual had out of date contact details or had left the service. All staff in phase one and parents and paediatric staff in all phases were recruited as a result of their recent involvement in the paediatric screening project.[17]

Study phases

The present study comprised of five phases. Table I provides an overview of each, including participant information, inclusion criteria, recruitment, data collection and analysis. The first phase involved a literature search to inform the broad areas that should be initially included in the study. In the second phase feedback from a sub-sample of parents and staff who had participated in the paediatric screening project[17] was obtained. In the third phase, semi-structured interviews[23] were conducted to obtain more detailed views from a sample of those participating in phase two. In addition, the expert sample was widened in order to obtain the perspectives of other service providers and professionals, particularly teachers and researchers. This was because the phase two participants highlighted the wider impact of screening on other services, particularly schools. In line with recommendations for qualitative aspects of Delphi studies, sampling for the semi-structured interviews was purposive, responses were anonymised and data were analysed using thematic analysis.[23]

INSERT TABLE I

In the fourth phase, the areas of impact (both positive and negative) identified in the first three phases were used to generate a series of impact questions. Participants were asked to rate the extent to which they agreed with the statements. The options were 'agree', 'neither agree or disagree', 'disagree' or 'not applicable'. For this phase, only those with experience of the CAIDS-Q being used were invited to participate.

The final phase addressed the second aim of the study – to use the agreed framework in order to assess the impact of screening on those who participated in the paediatric screening project. In this phase, which took place approximately two years after the end of the paediatric screening project, the data from parents and paediatricians in relation to the final questions were analysed. In addition, examples of impact relating to each category

(where available) provided by parents and paediatricians were identified. All paediatricians and those parents whose children had been diagnosed with an intellectual disability were also asked to provide overall ratings of the benefits. Ratings were 0-100, with a higher rating indicating a greater perceived benefit.

Data analysis

Levels of agreement used to determine stakeholder consensus vary widely in published literature.[22] In the present study, an item was retained in the final survey if it was endorsed (i.e., the 'agree' response was chosen) by 60% or above of all participants or 60% of the parent participants, excluding not applicable responses. This was because some items related specifically to parental experiences e.g., screening facilitated additional support for the child or was only asked of staff participants e.g., research.

Results

Of the original 20 questions, 12 were endorsed by over 60% of all participants in phase four or by either the parent or service staff group. These items were retained for phase five. The aim of this aspect of the study was to determine if the survey could capture the range of impacts of screening for intellectual disability for parents and paediatricians. Table II illustrates the parent and paediatric responses to the impact questions that were retained in the survey for phase five of the study. Examples of the type of impact reported by parents and paediatricians are also provided. None of the questions relating to negative impacts of using the CAIDS-Q were retained (i.e., causing stigma for the children, being used inappropriately instead of diagnostic assessment, being used inappropriately as a way of limiting access to services) as endorsement was 12% or less.

INSERT TABLE II

Phase five: Overall benefits of screening for intellectual disability

Nine parents reported that their children were newly diagnosed as having an intellectual disability as a result of participating in the paediatric screening project (5 additional parents were unsure if their child had a previous diagnosis). The ages of these children ranged from 8-14 (mean = 11.4 years, SD = 1.9). Table III illustrates ratings of benefit for those children who were not previously known to have ID who were diagnosed as such as a result of screening and the overall benefits as rated by paediatricians.

INSERT TABLE III

Discussion

The project aimed to develop a consensus framework and then use this to assess the impact on parents and paediatricians of participating in the paediatric screening project.[17] The first aim was partially achieved, with an iterative modified Delphi approach resulting in 8 out of 12 questions that were endorsed by over 60% of all stakeholders. Two items were seen as mainly applicable to parents because they reflected their personal experience in relation to quicker diagnosis and additional support for their child. Similarly, the questions relating to research and prioritising diagnostic assessment were more relevant to service staff. An obvious additional perspective that was missing was that of children with an intellectual disability. The main reason for this omission was that, while the online questionnaire allowed views to be obtained from parents who were geographically dispersed, this method would not have been feasible as a way of obtaining the views of the children with an intellectual disability. This was because accessing and completing the questionnaire required a level of technical and literacy skills which most of the children would be unlikely to have. Future research is needed to determine if the framework is consistent with their perception of the

impact of screening for intellectual disability. It is likely that this would be best achieved through individual interviews with the children. Unfortunately, the project team did not have the resources to use this method in the present study.

The most strongly endorsed items for parents, in terms of their perception of the impact of screening for intellectual disability was that it gave an indication of the child's level of functioning, followed by increasing awareness of intellectual disability and helping to identify children who were not previously known to have an intellectual disability. All of the paediatricians endorsed the first and last of these items, along with the item relating to identifying potentially vulnerable children. These items all relate to the direct impact of the screening questionnaire, rather than the associated benefits that are a result of subsequent diagnostic assessment. These then, might be considered the primary benefits of screening for intellectual disability. Research with the CAIDS-Q has shown that it has good sensitivity and specificity when used in paediatric settings,[17] therefore achieving its main aim of helping to identify children who have an intellectual disability. In terms of indicating level of functioning, research has shown that it can be used to give a broad indication of severity of intellectual disability,[24] functional ability[25] and level of cognitive functioning[12] and that it correlates more highly with measures of IQ and adaptive functioning, than these measures correlate with each other in a paediatric sample.[17] In addition, explaining the purpose and nature of the screening process may, in itself, increase awareness of intellectual disability. This is important, as research suggests that knowledge about intellectual disability is low in key groups who would be in a position to facilitate the early identification of the condition, such as primary care staff[26] and teachers.[27]

There were also a number of important secondary benefits of screening i.e., that followed from the diagnostic assessment associated with the screening, rather than directly from the screening itself. These included greater understanding of the child, the identification

of the support needs of the child and family and receipt of additional support, particularly for the child at school. These areas are consistent with many of the therapeutic and psychoeducational benefits that have been associated both with diagnosis per se and early diagnosis. [5,6,7,8]

Both parents and paediatricians provided high ratings for the overall benefits of screening for intellectual disability. They appeared to see the benefits from the perspective of the child, with the highest ratings being for advantages for the individual child/children with an intellectual disability. The second highest rating from both groups was in relation to other services, such as schools. This is reflected in the comments provided, where many parents and paediatricians reported outcomes such as being able to argue for, and in many cases receive, additional or different types of support for the child at school.

While some potential disadvantages of screening for intellectual disability were identified throughout the different phases of the project, for example screening being stigmatising for the child, being used inappropriately instead of diagnostic assessment or for gate-keeping purposes, these were only endorsed by at most three people. It would appear, therefore, that screening has a number of advantages, but no significant disadvantages, at least amongst the participants of the study. It may, however, be that disadvantages arise or are more commonly encountered as the CAIDS-Q is introduced to new service settings. As such, the evaluative framework requires the flexibility to incorporate both new disadvantages and advantages. At a basic level, this might include the option for participants to provide comments under an 'other' category within the framework.

The study did have a number of limitations. Some of these relate to the nature of Delphi approaches, including the extent to which the participants are representative of all relevant stakeholders. As responses were anonymous, the characteristics of non-responders

are unknown and their views may have differed from those of the participants. In addition, as noted previously, our study did not include the perspectives of children with an intellectual disability. In addition, while the CAIDS-Q is used internationally (e.g., The Youth on Track Model[28]), only one participant was from out with the UK, meaning there may be a geographical bias to the results. For example, low and middle income countries may lack well-developed referral pathways for diagnostic assessment. In such cases, screening may be used more widely to identify children with a broader range of developmental difficulties, rather than having a specific focus on people with an intellectual disability. Even within the UK, factors such as the availability of diagnostic assessment services and the actual and perceived cost-effectiveness of screening are likely to influence the extent to which screening is viewed as beneficial. While earlier research into the economic impact of early intervention suggests that there are greater lifetime financial costs incurred from failing to identify children with a disability than overidentifying them,[29] a further important area of research is to establish the cost-effectiveness of the CAIDS-Q.

The focus of the present study was on screening for intellectual disability in children, but similar issues exist for adults.[30] Further research using the impact framework with adult services and in other countries can help determine if there are cross-cultural or service setting differences in the areas that are prioritised for measuring impact.

A further consideration is that, as part of the paediatric screening project, the adaptive and intellectual functioning of the participating children were assessed and feedback was provided to parents and paediatricians in a way that promoted increased understanding of the support and learning needs of the child. This may not reflect routine practice in other services, where a major challenge may be obtaining diagnostic assessment for children with an intellectual disability in a timely way, resulting in delayed diagnosis[10] or that assessment is conducted in an unhelpful way that does not inform the needs of the child.[31] Indeed, nine

parents reported that their children had not been diagnosed prior to taking part in the paediatric screening project, despite being aged between 8 and 14 years. Similarly, a number of paediatricians commented on the challenges of routinely obtaining diagnostic assessment. Despite these potential differences in diagnostic assessment across services, the pattern of endorsement of items by staff from services other than those where the paediatric screening project took place, was the same as that for the paediatricians and parents, suggesting that the benefits are likely to be applicable across service settings.

This does, however, highlight the need for a coordinated approach to screening and assessment of intellectual disability. As Guralnick[8] notes in relation to early intervention, there is a need to integrate policy, practice and the existing evidence base to develop and provide a framework for effective early intervention, of which early screening and diagnosis must form an integral part. Screening for intellectual disability, in the absence of subsequent timely diagnosis and intervention can only have a limited impact.

In addition, while research suggests that early diagnosis and intervention is important, the validation of the CAIDS-Q has focused on children and young people from age 6. At this age the stability of IQ increases,[32] meaning that the accuracy of diagnosis of intellectual disability is also likely to improve at this age. This decision reflects the challenge of reaching a balance between the need for accurate screening and early intervention.

In conclusion, the present study found that it was possible to develop a consensus framework of 12 items that are relevant to measuring the impact of screening for intellectual disability. Using the framework to measure the actual impact on those who had participated in a paediatric screening project found four items that were more relevant to the subgroup of parents (facilitating early diagnosis and additional support) or staff (benefits for research and prioritising diagnostic assessment). The most highly endorsed items could be conceptualised

as ‘primary’ benefits of screening i.e., resulting directly from the screening process, while others were secondary i.e., resulting from subsequent diagnostic assessment. Overall, a number of benefits and no significant drawbacks of the screening process were identified. The framework was developed specifically in relation to the use of the CAIDS-Q and used to evaluate impact as used in a particular setting- paediatric services in Scotland. A number of areas of future work were identified, however, which may allow the framework to be used more broadly as part of evaluating other intellectual disability screening programmes.

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Table I: An overview of each phase of the study including participants information, inclusion criteria, recruitment, data collection and analysis

Phase	Participants	Demographic Information (where available)	Purpose	Inclusion Criteria	Recruitment and data collection method
I. Literature review	N/A	N/A	To identify relevant topic areas to include in the survey.	N/A	N/A
II. Feedback from staff and parents who had participated in the paediatric screening project	Feedback obtained from parents (11), and child health professionals (7) and teacher (1)		To obtain initial feedback on benefits and drawbacks of screening from those who had direct experience of the use of the CAIDS-Q in paediatric services.	Parents: Their child had participated in the paediatric screening project a minimum of 18 months prior to being invited to take part in the impact survey. Staff: Those staff who supported the greatest number of children who had participated in the paediatric screening project.	Participants were provided with information about the study via existing contact details held as part of the paediatric screening project Participants could provide their views about the impact of screening via email, telephone or face to face with a researcher.
III. Semi-structured interviews with staff and parents	Interviews (n = 19) were completed with: Service staff (n = 15) comprising health staff (community	*Service staff* age range 21-67; male = 2, female = 13	To further explore some of the themes identified in phases I and II with a wider group of parents and service	Education staff: teachers in the participating schools which supported	Education staff at the two participating schools were contacted initially by email and provided with details about the study.

	paediatrician, applied psychologist), one clinical researcher; one service manager; eleven teachers (nine from a special school, two from a mainstream school).
	
	Parents (n = 4)
		Ten had experience of working directly with children with an intellectual disability.
		
		Parents
		male = 1, female = 2;
		
		unemployed = 3; full-time employment = 1;
		
		Age of children 8-13 (mean = 10.2, SD = 2.2).
			providers- in particular education staff.
			
			To explore whether the themes identified in phases I and II were comprehensive and would address impact in other services.
				children with an intellectual disability.	Other service staff were identified as using the CAIDS-Q in their service from previous contact with the first author.
					
					Parents were contacted via existing details from the paediatric screening project.
					
					In all cases, participants were provided with information about the study by email, given the opportunity to ask questions and a suitable time to conduct the interview was arranged.
					
					Interviews were semi-structured and addressed areas of impact identified in phases I and II. Participants were invited to identify additional areas. Data were analysed using thematic analysis.

IV. Creation of questionnaire	This was completed by: Service staff (n = 14) comprising five applied psychologists, three of whom also engaged in applied research; three clinical researchers; six paediatric staff, one	*Service staff* female = 14 age range = 26-67 (mean = 42.7, SD = 10.1) *Parents* female = 27; male = 4	To establish if a consensus could be reached by parents and service staff about the most important areas of impact of screening for intellectual disability.	*Service staff* Had experience of the CAIDS-Q being used in their service. *Parents* Their child had participated in the paediatric	*Parents and paediatricians* Contacted via existing details. Those participating in phase III also participated in this phase. *Other service staff* Contacted as per phase III. Those participating in phase III also participated in phase IV.

	community service manager. Parents (n = 31)	age range 31-56 years (mean = 43.5 SD = 7.4) employed = 20; unpaid carers/homemakers = 6; unemployed = 3; retired = 1; student = 1 *Child characteristics* age range 7-14 years (mean = 11.5, SD = 1.9) male = 23; female = 8		screening project and had been identified as having an intellectual disability.	Participants were emailed a link to the online survey and asked to complete it. Data were analysed using descriptive statistics. Items that had over 60% agreement for the whole group or for either the parent or service staff group were retained for the phase V.
V. Using the questionnaire to identify impact	Parents (n = 31) and paediatricians (n = 6)	Parents- As for phase IV Paediatricians: Females = 6 Age range = 35-50 years (mean = 42.5, SD = 5.9)	Based on the included questions, the specific impact of the paediatric screening project, as reported by participating parents and staff was summarised.	*Parents*: As for phase IV *Paediatricians:* Children they had supported had participated in the paediatric screening project	Data from the phase II survey were analysed in respect of the retained questions.

Table II: Participant responses in terms of benefits of the screening process

Benefit	Percentage of participants agreeing with each item		Sample comments (comments by paediatricians in italics) Note: 'learning disability is one of the term used in the UK to refer to 'intellectual disability
	Paediatricians	Parents	
Increasing understanding and acceptance			
Helps to identify children who were previously not known to have an intellectual disability	100	77	'Confirmed my intuition' 'That I finally had an answer to what was wrong with my son'
Increases awareness of intellectual disability	83	80	'That we could finally put a name to what he had' 'Being able to give his condition a name'
			'Very pleased to have clarity of her learning disability'
			'*Clarity about learning ability, particularly in older children where paediatrican has fewer tools/skills to assess'*
			'Most school aged children/ young people with learning difficulties in these days do not have cognitive assessment by Ed Psych [Educational Psychologist] so participation in study was the only way for families to get answer/ advise'
Helps identify potentially vulnerable children	100	73	'Know what her weaknesses are'
			'It gives us a better understanding of his learning needs and also a better understanding of where the problems lie'
			'It gave a better understanding as to what level our child was functioning on, both for ourselves and others that care for him'
			'*It helped provide a clearer understanding of him and helped mum understand the reality and extent of his difficulties'*
			'*It gave the child's parents great reassurance and in some ways acknowledged the level of support and differentiation that has been required in and out of school'*
			'*There is a real need for this type of assessment for so many children who otherwise 'fall through the gaps''*
Gives an indication of the child's level of functioning	100	81	'Understanding our child's behaviour better. Learning to accept her as she is'
			'I was able to understand [child] a little more'

			‘A better understanding and more patience with him after realising his school difficulties were arising from frustrations’ ‘Being able to understand why [child] is why he is’ ‘*Gave family and professionals better understanding of child’s needs’* ‘*…giving us a better picture of some of the many children that we assess where there are concerns about their learning’* *‘The psychological assessment was very good at highlighting the patient’s areas of strength as well as difficulty and this crystallised mum’s concerns and helped her to understand how better to support her daughter’* *‘They simply want to be able to express meaningfully the level of difficulty he experiences with everyday living and learning tasks’*
Helped the child receive diagnostic assessment more quickly	17	62	‘Very helpful process. It really helped with my daughter’s diagnosis. She saw (paediatrician) two days after the assessment and (paediatrician) incorporated the feedback into her assessment.’ ‘*It can be very difficult to access a psychology opinion for assessing and supporting a child due to NHS waiting lists and priorities’*
Informing support needs and increasing support for the child and family			
Helps inform the support that is needed for the child	83	65	‘Because of this he was eventually diagnosed with Autism and the school knew how to manage with his development better’ ‘The school being more aware of his needs’ ‘IEP {individual Education Plan} better adjusted to aim at intellectual level’ ‘To have the term 'intellectual disability' written down, in order that this can verify that our child needs support in Education. It will be on our child's medical record for future support if offered’ ‘Provides more weight to our case for additional support at school’ ‘Without this service we would never have been able to get our child's IQ checked to get a definite diagnosis of a low IQ resulting in moderate learning difficulties. It was obvious that there were difficulties but this helped to back everything up for both the family and the school’

			‘Felt it gave a passport to at least be knocking on some doors for help’ ‘*A child who was struggling at school but did not seem to have had any assessment of learning and whether the behaviour was being influenced by an underlying learning disability*.’ ‘*We often struggle to get the school to refer to their Educational Psychologist, so the results are helpful in getting things moving in school from our point of view’* *‘“The research provides concrete information regarding CYP [Children and young people] who are not managing the standard school curriculum”* *‘It contributes to information which is helpful for education colleagues/ other involved professionals in identifying particular areas of difficulty’*
Helped the child get additional support	n/a	62	‘It has also helped in applying for a SEN high school placement request’ ‘It helped with the case (application) for admission to special school’ ‘Allows access to additional support at school’ ‘My son has a problem with dogs and we had tried to get assistance with this issue, but it wasn't until he had his IQ test results we were then given {service} support for him’ ‘Getting the right support at primary school and transition to the right secondary school’ ‘This has helped with his application to secondary school to prove that he has a diagnosis of an intellectual disability which backs up all the other professional reports we have received over the years’ *‘Allowed family to access specialist school placement for their child; Allowed access to other services and supports’* *‘The reports have been helpful in advocacy for several children”*

Helps inform the support needs of the family/carer	83	62	‘More understanding from stakeholders i.e., my employer, the school, neighbours, friends and family etc.’ ‘Introduced to support from charities that were never mentioned when he just had ASD diagnosis’ ‘Getting more respite care’ ‘It allows for a greater support package from social services (going from nothing to a little bit of help)’ ‘In addition, it helped with other applications, for example for extra support (incl. financial), etc.’
Increasing wellbeing and addressing inequalities			
Contributes to increasing the well-being and life chances of the child	67	62	‘To help {child] and the family understand {child] and help him with appropriate tools’ ‘We were able to apply for a learning disability nurse for my child which is helping greatly in terms of life skills’ ‘Improved communication as care givers adjusted language and temperament for better results and cooperation’ ‘Being able to read up more on it and help him at home’ ‘Better understanding and tolerance, language adjusted to gain better communication and cooperation. Is able (at times) to play games with cousins etc... Which we were never able to achieve until after the understanding the study gave us, in turn could explain better to younger family members’ ‘Helped paediatrician also identify possible sensory only issues, due to understanding intellectual level better, allowing a change in daily activity diet’ ‘Felt this screening has been invaluable. I now have a better understanding of where my son is intellectually which has a positive knock on affect from how I ask him to brush his teeth, to what games and books to buy. It doesn't stop the struggles or issues having to be dealt with however it helps in strategic planning on coping or cooperation strategies’ ‘I think this screening test should be available to all individuals that possibly have a learning disability to give the parents/carers confirmation of this which in turn will open up other services’
Perceived impact on wider services			
Can be used by a range of people	67	65	

Helpful for research purposes	83	n/a
Helps the service prioritise diagnostic assessment	67	58

Table III: The overall ratings of benefits of screening for intellectual disability as rated by paediatricians and parents of those children who were newly diagnosed with intellectual disability.

Benefit	**Parents (n = 9)**	
	Range	**Mean (SD)**
Benefit to the child	50-100	89 (18.9)
Benefit to you/other family members	39-100	83 (26.5)
Benefit to paediatric services	45-100	75 (23.3)
Benefit to other services e.g., schools	50.00	86 (23.4)
	Paediatric staff (n = 6)	
Overall benefit to the service	50-100	78.3 (17.2)
Overall benefit to people with an intellectual disability within your service	70-100	88.3 (11.7)
Overall benefit to others impacted by your service	60-95	77 (13.0)